TBI TODAY



NEWS, IDEAS, AND RESOURCES FROM THE VIRGINIA TBI MODEL SYSTEM

THE VIRGINIA TBIMS TEAM

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DISCLAIMER:

The views expressed in survivor stories are of the author and reflect the author's experience. These do not necessarily reflect the views and opinions of VCU or it's researchers.

Art as Healing, Art as Heart

by Carmen Marshall

In 2013, I sustained traumatic brain injury. It has been a painful process finding and sustaining the self; struggling to construct meaning and purpose; and finally, partial acceptance of the tragic consequences of TBI.

The injury was debilitating physically and intellectually. The immediate impact was loss of balance, cerebella ataxia, vertigo, proprioception issues, vision difficulty, and pain. As an English professor and published author, it was devastating to realize I couldn't read. The words on the page looked like jumbled "SSSSSSS." Consequently, I signed documents without knowing the contents, ashamed to admit I could not read though I could write. Imagine the shock on discovering I couldn't draw a clock; couldn't track numbers 1-15. Add Low Vision, Tremor, hospitalization, sub-acute nursing facility, different therapies, the loss of the ability to drive and watch TV to the mix, and you enter a topsy-turvy world. You are asked: "Can you touch your nose?" You are assisted in crawling! So who is this new person who now inhabits your body; who cannot make its right and left sides communicate meaningfully? Who has difficulty walking?

My art reflects some of my experiences as a TBI patient and my friends encouraged me to share my experience with others. It began primarily to facilitate healing--hand eye coordination; overcoming nausea, dizziness and headaches when seeing intricate patterns, alleviate boredom etc.; but it was also an attempt to find meaning and ultimately, transcendence.

The prognosis is daunting, but I focus on the ETERNAL NOW as often as possible.

See examples of Carmen's work below and throughout this issue of TBI Today, also found on our website. To contact the artist about her work, email: song993@verizon.net

G. B. G.:

GRAUMATIC
BRAIN-INJURY:

A CHRONIC-LIFELONG- DISEASE.

Fig 2 "DISGUISE" \rightarrow

"The iceberg symbolizes TBI with a sudden, devastating effect on contact. Its massive powerful body, hidden under water, remains for decades. The many levels of trauma impacts the patient's life and its duration and are invisible to many."

← Fig. 1 "NAME IT"

"At first, I didn't grasp I had a chronic disease. Indeed, the first neurological diagnosis reads: 'Assessment: It is my medical opinion patient sustained #1. Cerebral contusion. #2. posttraumatic headaches, #3. dizziness. #4. nausea. #5. lumbar sprain. #6 cervical sprain. #7. Abnormal neurologic examination with pronounced ataxia' But the other assigned physicians ignored the diagnoses. Later, they were confirmed by Johns Hopkins. A therapist assessing my efforts to get well and return to work cautioned: 'You cannot legislate to your body when it will heal. It will heal on its own."



RVA Adaptive Sports Festival

- When: March 26, 2022 10 AM 2 PM
- Location: J.R. Tucker High School
- Contact: Register Now at sportable.org, please direct questions to Shelley Sowers at shelley@sportable.org or call (804) 340—2991.

Wayne Samford Memorial Golf Tournament

- When: May 16, 2022, Registration & Range 9:30
 AM, Shotgun Start with Box Lunch 11:30 AM
- Location: Hunting Hawk Golf Club 15201 Ashland Rd, Suite 1606 Glen Allen, VA 23059
- Contact: To register, visit sportable.org/events.

Community Brain Injury Services' 12th Annual Lifting the Silence Gala

- When: May 21, 2022 6 PM- 9:30 PM
- Location: Maymont Nature Center—West Terrace 2201 Shields Lake Drive Richmond, VA 23220
- Contact: To purchase an event ticket, visit communitybraininjury.org/events.

BIAV Virtual Meeting Group

- What: For people living with brain injury, their family, and friends.
- When: Fourth Thursday of the month, 6 PM (EST)
- Contact: To join email Christine Baggini at christine@biav.net.

BIAV Caregiver Virtual Meeting Support Group

- What: For family caregivers only, receive support, strength and share your experience with others in the same position
- When: First Wednesday of the month, 6 PM (EST)
- Contact: To join email Debra Holloway at debra@biav.net.

BIAV In-Person Support Group

- What: For people living with brain injury, their family, and friends.
- When: Third Monday of the month, 6 PM (EST)
- Where: Willow Lawn Area of Richmond, VA
- Contact: If you're interested in joining this group, please contact Christine Baggini at christine@biav.net or (804) 355-5748. Registration is required in advance as they maintain COVID safety measures.

If you have an upcoming event of interest to the Brain Injury community in Virginia, we would be glad to consider including it here. Please call (804) 828-2377 or email laura.albert@vcuhealth.org.



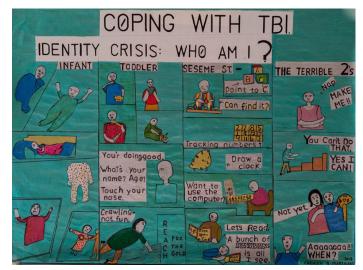
← Fig. 3 "HUMPTY DUMPTY HAS A TBI"

"Many adults fail to connect the nursery rhyme to the chilling reality of TBI as life-changing *and* lifelong."

Fig. 4 "TRIUNE FACES" →

"Three types of TBI: Mild, Moderate, Severe. Most cases are mTBI's, but MODERATE to SEVERE must deal with the sudden chasm from independence to dependency"





↑ Fig 5 "IDENTITY CRISIS"

"Patients experience *INFANCY*; being fed, bathed, dressed. If they live they enter *TODDLERHOOD*— learning to perform daily life skills. 'What's your name?' You're asked. 'You're doing good' is the encouragement you get when you can 'touch your nose.' It's *SESAME STREET AGAIN!* Identifying numbers and letters. And there's the *TERRIBLE TWO'S*,' 'You can't do that.' 'YES I CAN!'"



A Story of Resilience by Kara Keuthan Beatty, MD

Time can be perplexing. One minute I was eating dinner with my best friend and the next I was waking up in the hospital with my mother next to me. At least that's what it *felt* like. In actuality, I had been involved in a serious motor vehicle accident that would change the trajectory of my life.

June 19th, 2002 started out like any other day. I woke up to my alarm and then proceeded to get ready for the summer school class I was taking at the local community college. I have been told that it was a beautiful day, not the type of day that could almost take your life. I was driving to school and taking a left turn at a traffic light when an over-sized truck ran a red light. I cannot tell you what that impact felt like or what was running through my mind at that moment. All of my recollection comes from stories that have been told to me. Stories from the painter that witnessed the accident

and ran to my car with a clean rag to apply pressure to my forehead; and from the EMT providers that used the "jaws of life" to get me out of my car. I was transported to the hospital, where I spent the first 4 days in a coma. I regained consciousness the night before my 19th birthday. As my brain healed, I remained in a state of amnesia. Though I was alert and awake, I could not form new memories. During this time, I was transported to another hospital where you are greeted by pictures of TBI and SCI survivors. Early on in my stay, my mom took me down to admire these inspirational stories. I had not yet regained my ability to walk so I had to be pushed around in a wheelchair. She turned me around and said, "Maybe when you graduate from Texas A&M, they will put your picture up on this wall." I looked her straight in the eye and replied, "No. I plan to be a doctor one day." That was the same day that neuropsychological testing showed that I was at the reading level of a 4th grader. But my mind had been made up; I was going to be a doctor.

After completing 3 weeks of inpatient rehabilitation and 5 months of outpatient rehabilitation, I was released to return to college. Though I was initially resistant, I eventually accepted that I needed accommodations to pass my classes and graduate. We often have the misconception that "doing it alone" proves our strength. I now believe that asking for help is one of the most courageous things you can do. Without help, I cannot imagine that I would have been able to graduate with honors and be prepared for the next chapter of my life, medical school. The most important lessons that I learned in medical school were not about biochemistry or immunology; they were about advocating for myself and moving forward after hardship. With much persistence, I graduated from medical school and landed a spot in residency for Psychiatry. It is in Psychiatry that I found my passion. I was named Chief my final year of residency and transitioned into a fellowship in Brain Injury Medicine. After my fellowship, I embarked on a new adventure: starting my own practice. Now, three years later, my practice is thriving so I can continue in the direction of my dreams.

A day does not go by without a reminder that I have a TBI. Whether I struggle to retrieve a word or find myself getting fatigued by 3PM, it is always present. My story is not one of triumph; it is of overcoming. I have had many challenges and still do, but have found ways to overcome them so that I can live the life I want. I share my story in hopes of inspiring others to do the same.

Finding a New Path by Cheryl Dean

Five years and counting since my TBI in 2017, when, as a pedestrian, I was hit by a truck. I was airlifted and then in a coma for 9 days during which I also had a stroke, followed by relearning to do everything through physical, occupational, and speech therapy. Someone asked me the other day if I was 100%. As fellow brain injury survivors, you know that's what some people may expect if our injury is invisible to see. It helps to know there are many others out there that understand this frustration. While I may not fully be the way I was before that life changing experience, I remain complete with strength, intellect, resilience, empathy, and determination. I am not going back to the person I was, but moving forward with a greater appreciation for life and abilities.

It helps to remind ourselves how far we've come and find a renewed purpose. I was honored to serve on the Brain Injury Connections of the Shenandoah Valley board of trustees for a 3 year period, and continue to serve as a member of the Greater Shenandoah Valley Brain Injury support group. I had the privilege of sharing my story with organizations, churches, and legislators at the General Assembly in Richmond. It is satisfying to know we can make a difference as individuals and be an active part of the community in which we live. Sharing one's journey can help others on a similar path and can bring meaning to one's own experience.



Challenges are a part of life. Like many, I was fortunate to have survived the Omicron COVID-19 virus this year with the help of monoclonal antibody infusion. I'm at greater risk due to having multiple sclerosis. Even still, my daily gratitude journal continues to fill with much to be thankful for. The path may not be smooth or easy, but learning to navigate even the toughest terrain is so worthwhile. Keep on traveling!

DEAR PAT,

I have a brain injury from a motorcycle accident back when I was 25. I was young and reckless, and thought I was invincible – don't all 20 year olds? Looking back, I'm thankful that I survived the accident. It wasn't an easy road to get to where I'm at now but I know I'm better off than many people I know who were in motorcycle crashes. I have my own place, a car, and even a fiancé. I would say I have a "normal" life like other people in their 30's, except...

Work...I have not been able to keep a job since my accident. I was working as an accountant when I got hurt. I tried to go back to work, but had a hard time keeping up with the deadlines due to my cognitive changes. Over time, my employer saw my limitations and let me go. The reason they gave was my performance was sub-par.

The trouble is that nobody understands brain injury and the difficulties I experience daily. Most of the time, I'm hesitant to tell my employers about my accident, hoping it wouldn't be a factor. Since I look pretty good on the outside and sound good during the interviews, I'm able to get hired based on my resume and experiences. The problems come up after about a month or so when I can't keep up or make mistakes. It's hard to build trust and be given room for errors when you're a new employee.

Well, after many failures, I decided to become an independent contractor and do freelance work, which works pretty well but the money isn't steady. I get too stressed out because I don't know if I'll make enough money to pay my rent. So now, I'm considering going back into job market for full-time work and need some advice on how to hold steady employment.

When starting a new job, what are your recommendations with sharing or not sharing about your disability? What rights do I have as an employee with a disability? What about using a job coach, where could I find one?



Pat answers your personal questions about brain injury with compassion and practical advice. However, advice from Pat's column should not be substituted for consultation with a doctor or rehabilitation specialist. The identity of individuals submitting questions to "Chat with Pat" is kept strictly confidential.

PAT'S RESPONSE:

Thank you for sharing your story with me. I commend you for your persistence and fighting to make a steady living for yourself (and your future spouse). Working and feeling like a productive member of the society are important to all of us.

First, I recommend meeting with a vocational counselor who can help you identify your personal interests and skills, and then match your interests and skills to jobs that would be a good fit. Finding a job that you like and are good at will be the key to long-term success.

With regard to disability rights, I recommend that you become familiar with the Americans with Disabilities Act (ADA) and your rights as an employee. Information about the ADA may be found at most public libraries or at the following web address, ADA home page: http://www.ada.gov. You can go to ADA Overview under Technical Assistance Materials, then download: A Guide to Disability Rights Laws. This 21-page booklet provides a brief overview of ten Federal laws that protect the rights of people with disabilities and provides information about the federal agencies to contact for more information. A Guide for People with Disabilities Seeking Employment is a 2-page pamphlet for people with disabilities that explains the employment provisions of the ADA and how to file a complaint with the Equal Employment Opportunity Commission

For those who are self-employed with a small company, you may also find this information useful. *ADA Update: A Primer for Small Businesses*. This 24-page illustrated guide presents an overview of 2010 ADA requirements for small businesses that provide goods and services to the public.

Toll-Free ADA Information Line: Call to obtain answers to general and technical questions about the ADA and to order technical assistance materials:

800-514-0301 (voice); 800-514-0383 (TDD)

To find out about job coaching and other employment services for persons with disabilities in your state, you may wish to contact the state's Department of Human Services. Division of Rehabilitation Services.

After understanding your rights as an employee, you can decide how much and what to share about your injury with your employer. You may wish to consult and discuss your concerns with your treating healthcare professionals, including psychologist, neuropsychologist, therapist, or rehabilitation counselor, regarding your decision to share or not share about your injury. If you decide to share, you may wish to share documentations of your disabilities or limitations, such as a neuropsychological report, with your employer or trusted colleagues to prevent problems from arising in the future. Creating a collaborative relationship with the Human Resources department and your supervisor is important to establishing a positive working environment.

7 Little Words°

Find the 7 words to match the 7 clues. The numbers in parentheses represent the number of letters in each solution. Each letter combination can be used only once, but all letter combinations will be necessary to complete the puzzle.

	Clues		Solution	\mathbf{S}		
1	lived with (9)					
2	skin softener (6)					S
3	texts (8)					
4	securing a sale ((7)				T
5	be involved in (1	.1)				O
6	Oprah's bestie C	Gayle (4)				J
7	it's held down by	y laces (6)				
	TED	ON	IPA	NG	TIC	
	TI	SI	NG	CLO	KI	
	ERA	MES	SAG	LO	GUE	
	TON	TOL	TE	PAR	ES	

See the solution on page 7

Frequently Asked Questions

THE INFORMATION PROVIDED IN THE FAQ IS INTENDED TO FAMILIARIZE THE PUBLIC WITH ISSUES RELATED TO TBI. NO INFORMATION PROVIDED HEREIN SHOULD BE CONSTRUED AS THERAPEUTIC ADVICE OR AS A SUBSTITUTE FOR CONSULTATION WITH A COMPETENT MEDICAL OR MENTAL HEALTH PROFESSIONAL.

QUESTION:

My memory has been awful since my brain injury. I will walk into a room and forget what I'm looking for. What can I do?

ANSWER:

You are not alone. Forgetting what you are looking for is a common problem reported by persons who have had a brain injury and even with people who haven't. Here are some strategies for remembering what you are looking for:

- Avoid trying to do too many things at once. It is sometimes easier to forget or get confused when you are trying to do different things at the same time.
- > Repetition. Repetition. Repetition. Repeat the name of the object of your search to yourself over and over until you find it.
- Write down what you are looking for. Even just one word may be enough to trigger your recall.
 - * If paper is not handy, write on your hand.
 - * If a pen is not handy, "write" with your finger.
 - * Text or email yourself or someone you are close to.
- > Take something with you to remind you what you are looking for. For example, if you are looking for your checkbook, take the bill you intend to pay.
- "Retrace your steps." For some, going back to the "starting line" helps them recall what they are looking for.
 - * Walk back to the last place you remember being. Look all around.
 - * Try to form a picture in your mind of what you were doing. Were you sitting or standing? Were you alone or with someone?
 - * Pantomime or "act out" what you were doing (e.g. writing something down, opening a drawer, opening a drawer, leafing through a book).
- > Organization. When things have a "home" it becomes habit to put them there and easier to find when you need them.

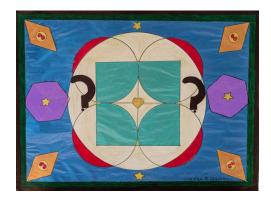


← Fig. 6 "CHAOS"

"Fear, anger, uncertainty, bewilderment with conflicting diagnoses, etc. generate confusion."

Fig. 7 "GAINING CONTROL" →

"With great effort, you anchor some guideposts. But questions remain."





←Fig. 8 "MY WILL, MY COACH"

"Regaining selfhood is hard, lonely work."



←Fig. 11 "CLUTTER"

"The injured brain needs calm. It reels with *four types of clutter*: excess items, stress-inducing people, activities generating mental overload, and cognitive clutter."



←Fig. 9 "LIMITATION"

"Progress is slow, incremental. You push beyond plateaus."



←Fig. 12 "NECESSITY"

"To engage time inexorable, I choose hand-sewing non-traditional quilts to facilitate the 8 years of relative isolation. I enjoy the creative process, but the grunge aspects results in band-aids on fingers, low-visions frustration, and errors. Two sides of the same quilt."



←Fig. 10 "PERSERVERANCE"

"I began drawing with large crayons. I progressed to intricate shapes and lines which cause nausea, headache, dizziness. After three days in bed, I try again — a million times. The brain allows *some* change."



←Fig. 13 "THE PATH"

"Each person moves to their own drum, contributing to the "music of the spheres." With beauty, time connection/communication, food, the sun's energy, water, dwelling—all having spiritual undertones—the individual engages destiny."



Questions for Pat or the FAQ column are welcomed.

Send them to:

"ASK PAT" OR "FAQ"

P.O. BOX 980542. RICHMOND, VA 23298-0542

or e-mail: laura.albert@vcuhealth.org



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Survivor Stories Wanted!

Recovering from a brain injury can be very difficult. Sometimes, one of the most helpful and inspiring things is simply hearing from other survivors who have gone through recovery and faced the same challenges. Are you a survivor with a story you'd like to share? If so, then we'd like to hear it, and it might get into a future issue of TBI Today!

Submit to: laura.albert@vcuhealth.org

or

TBI Today, VCU P.O. Box 980542 Richmond, VA 23298-0542



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We're here for what comes next.

The human brain is extremely complex. So, it can be difficult to know where to begin when it comes to navigating life after brain injury.

That's where we come in.



We provide free and confidential resources and support to people with brain injuries, caregivers, and health and human service professionals.



We work to raise awareness, advocate at the federal, state, and local levels, and offer community connection through membership.



We offer professionals guidance for their patients and continuing education through conferences, webinars, and workshops.